



**ALS NEW BRUNSWICK
AND NOVA SCOTIA**

LIVE YOUR BEST LIFE GUIDE

www.alsnbns.ca

www.alswalkstrong.ca

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Brunswick and Nova Scotia)

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Table of Contents

I've Been Diagnosed with ALS

- YOU ARE NOT ALONE!
- ALS NB & NS is here to help you and your family navigate through a confusing and difficult disease with dignity and purpose.
- We will help you manage your health and live your best life in the face of your ALS diagnosis.
- We have the information and resources you need to get the most from your life.

You may have ALS but ALS doesn't have you. You are so much more than a disease. Please contact our ALS Champion today to enrol to receive our services or just to talk to someone.

**Important note – enrolment in the ALS Society is free as are all of our services. The ALS Society of NB & NS is a non-profit organization not funded by any level of government. We are supported by the generosity of people and organizations in our provinces who care about your quality of life.

Phone: 1 (902) 454-3636

Toll Free: 1-866-625-7257

Terri Cooper

ALS Champion- NB

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The First Steps

If you are reading this you have either been diagnosed with ALS or are in the process of being tested for ALS. Understandably, you are feeling shocked, overwhelmed, and full of anxiety.

There are three things you need to know right away:

1. You still have **life ahead** of you – yes, there are challenges ahead that will need to be faced and overcome but there is still joy and love and beauty in life.
2. You may have ALS but **ALS doesn't have you**. You can do amazing things!
3. It is important to work with your medical team, your family, friends, and the ALS Society of New Brunswick and Nova Scotia to maintain your independence, to keep up with volunteer work, to travel, to do many of the day to day things you do now.

Some people will want to know every single fact about ALS as fast as they can absorb it. Others will want to take things more slowly. You know yourself better than anyone else. Do what feels best for you.

What Is ALS?

- Amyotrophic Lateral Sclerosis; also known as Motor Neuron Disease (MND) or Lou Gehrig's disease after the famous baseball player.
- ALS destroys the motor neurons which are an important link in the nervous system. Motor neurons send messages to your voluntary muscles (those muscles you control like your arms, hands, legs) as opposed to involuntary muscles like your heart.
- In 90% of cases, ALS occurs randomly in the general population. It is known as sporadic ALS. In 5 – 10% of cases, the disease is inherited and known as familial ALS.
- Out of every 100,000 people, 6 – 8 will be diagnosed with ALS.
- ALS does not affect your five senses – sight, hearing, taste, smell, and touch.
- ALS is not contagious.

Symptoms and Signs

- Tripping, dropping things, slurred or “thick” speech.
- Muscle cramping, weakened reflexes.
- Difficulty swallowing.
- Shortness of breath at rest.
- Decreased muscle tone.

How Long Will I Live with ALS?

- Every case of ALS progresses differently. No one can predict how long you will live, not even your medical team.
- Most people will have a life span of 2 – 5 years, some shorter, some longer. There have been people in Nova Scotia and New Brunswick that have lived more than 10 years.
- The most important tools you have are your family support, your positive spirit, and if you are up to the challenge, your knowledge about the disease and willingness to accept nutritional, breathing, and other types of intervention and assistance with equipment.
- ALS NB & NS is a positive group of caring people that want to help you live your best life as long as you can.

Treatments & Drugs

There is no treatment that will slow progression of the disease but there are treatments, strategies and equipment to make you as comfortable as possible and aid in breathing, mobility, and communication.

Your multi-disciplinary team at the ALS Clinic will be of great assistance helping you make decisions about interventions and equipment.

ALS Clinic Contact Information:

New Brunswick – The Stan Cassidy Centre for Rehabilitation

Tel: 506-447-4082

Nova Scotia – Capital District Health Authority – Queen Elizabeth II Health Sciences Centre

Tel: 902-473-5565

What Causes ALS?

In ALS, the nerve cells that control the movement of your muscles gradually die, so your muscles progressively weaken and begin to waste away. ALS is recognized as having multiple interacting causes.

Researchers are studying several possible causes of ALS, including:

- **Gene mutation.** Various genetic mutations can lead to inherited ALS, which appears nearly identical to the non-inherited form.
- **Chemical imbalance.** People with ALS generally have higher than normal levels of glutamate, a chemical messenger in the brain, around the nerve cells in their spinal fluid. Too much glutamate is known to be toxic to some nerve cells.
- **Disorganized immune response.** Sometimes a person's immune system begins attacking some of his or her body's own normal cells, which may lead to the death of nerve cells.
- **Protein mishandling.** Mishandled proteins within the nerve cells may lead to a gradual accumulation of abnormal forms of these proteins in the cells, eventually causing the nerve cells to die.

Source – mayoclinic.org

After the Diagnosis – Coping with ALS

- Give It Time and Patience

A diagnosis of a terminal illness like ALS takes time to process both for the person diagnosed and for family and friends. Every person will process the information differently and so patience and space to process the information is required on the part of all family members and friends. Be kind to yourself and allow yourself to experience and go through the process of denial, anger, sadness and grief.

It's perfectly normal to grieve. Just don't unpack your bags and live there. Cry, scream it out, write it down, do what you have to. Then, refocus your energy to living your best life as well as you can, as long as you can. And remember, ALS NB & NS is here to help you.

- **ALS Does Not Define You** – ALS is part of your life – but not all of it. You are still the same person you always were. Fight for that person.
- **Maintain Positivity and Hope** – You're a normal human being and you're not going to be able to be positive and hopeful every day. But practicing and focusing on what is still good in your life, choosing a positive thought over a negative one, putting a smile on your face even when you don't feel like it can change your day (and the day of your family and caregivers) around for the better.

Meet Darrell. When Darrell could no longer work in sales (because he lost his voice); he returned to a lost love – photography. He spent many days at Nova Scotia’s beautiful beaches and parks, giving him a purpose and bringing him peace. Darrell’s beautiful work hangs in the office of ALS NB & NS and can be viewed/ordered at <http://www.easternlight.net>



- **Maintain a normal routine.** Okay, a “new” normal routine.

If weekly family dinners were at your house, keep hosting them as long as possible. Maybe the menu is less complicated, maybe you ask for help preparing food, maybe you sit back and let others bring the food. You may not be able to play hockey anymore but could you go to the rink once in a while to cheer your teammates on? Ask for help maintaining as normal a routine as possible. People want to help – you give them a gift by letting them know what help is useful. Remember, you would do the same thing for any family member or friend if the situation were reversed.

- **A New Perspective** – It is an unfortunate fact that you have a shortened life span. That fact must be acknowledged and grieved. However, many people with ALS find that it is helpful not to focus on the timeline but to embrace each day and each moment taking time to develop deeper relationships and explore your spiritual awareness.
- **Goals** – Setting some goals can assist you in making decisions about your medical treatment and how you wish to live your life.

Mike set a goal of living until his daughters graduated from High School. This helped him make decisions about medical interventions, when to accept assistive equipment and other help. Mike did achieve his goal living with ALS for 12 years.



- **Be Pro-Active and Knowledgeable** about the disease progression, the treatment and equipment available to reduce symptoms and make you more comfortable. Ignoring manageable problems or delaying intervention can make a difficult situation worse for both you and your loved ones caring for you.
- **The Gift of Sharing** – Share your diagnosis as early as you are ready to with family , friends, and children. Don't deny yourself the gift of support and love and don't deny those who love you the gift of caring for you in the ways they are able.
- **The Value of Connection and Experience** – Sometimes people delay joining a support group either online or person to person because they don't want to know what is ahead. Or if not a support group, being introduced to someone else with ALS. It can be difficult seeing what is down the road but it can also be very helpful. As an example some people with ALS may make decisions about future treatment without a full understanding of the implications of the treatment. Some people will say, when it's time for a feeding tube, I don't want to live anymore. And then they may meet someone with a feeding tube that is doing very well, traveling, attending their kid's sports events, still engaged in life. That might change your decision and give you hope. Also, family members and people with ALS are the best resource to offer practical advice and to lend you strength and comfort. At ALS NB & NS we have witnessed amazing friendships amongst our ALS families. Remember, it is not only the person with ALS that needs support but spouses, caregivers, and children.
- **Plan Ahead – The Difficult Decisions** - You and your family have a lot of decisions to make and plans to develop. This will require you to have hard conversations and to face end of life issues. Making these decisions early allows you to be in control about your life and care. It gives your family members and health care team direction when they understand and know your goals. It reduces stress as your care increases for your family members. Once the hard decisions and paperwork are out of the way you can move on with living your best life as well as you can as long as you can. And remember this, you can change your mind at any time. Interventions people thought they may not want at the beginning of their journey may change as treatments develop and as you gain strength and confidence about your ability to cope.
- **Seek Help from Professionals** – Seeking help (therapy or counseling) can offer a great deal of comfort and hope. Counseling and therapy sessions can be a safe place for you or your family to express fears, to learn how to cope with anxiety, to adapt to huge changes, to dealing with grief. Please refer to our Living the Gift Program under Programs and Services for more information.

- **Friends, Family, Children and Co-Workers – Breaking the News, Communication, Supporting Each Other**

Most people have the potential to have a great support system of family, friends, and co-workers. Please remember though that while they will not experience the physical symptoms of ALS with you; they are sharing the emotional ups and downs, the worries, the fears. Ultimately, you are in control of your care and disease management. The emotional and physical well-being however of your support system will play a part in your own ability to cope. Both are interconnected. Both rely on good communication, emotional support, give and take, shared decision making.

Let's face it – time is precious. Be open and direct with your support system in expressing your needs, wishes, fears, and emotions. In return, receive their expressions of the same without judgement.

Just like it takes a village to raise a child; it will take a team of family members, friends, and health care workers to care for you. Encourage your team members to take care of themselves physically and emotionally. Encourage your family to be realistic in the way they can help you and ask them to do things that are in their comfort level and wheelhouse.

Use humour to diffuse difficult situations. Laughter really is the best medicine.

An ALS diagnosis can be especially difficult for children of parents living with the disease. What is more difficult for those children however is when they are not kept informed at an age appropriate level. What children imagine is usually worse than the reality.

What is important for children is their daily routine. Being able to keep a routine for them will offer safety and security. Keep them informed of changes in the routine daily. Mom is taking Dad for a check-up today so Gramma will be here when you come from school. Next week, Dad is getting a wheelchair to help him get around. Dad can't use his voice anymore but he still hears and understands you.

While it is important not to overwhelm children, they can be involved in planning family activities and helping out at an age appropriate level. This helps them understand that family members support one another. That they can cope in difficult situations and be okay.

In one family we knew, the Dad with ALS taught his daughters (young teenagers) to do household repairs. He would observe and give instructions. They could fix his wheelchair, the snow blower, and tighten the bathroom taps!

At some point depending on their age children will need to know that ALS is progressing, that their loved one is going to die and how that will impact their life (who is going to take care of them, will they have to move, how are they going to remember Mom or Dad). It will be important to assure them that they will always be taken care of; that although you may get sad when they ask these questions, they can still ask them; that for a time you will be sad together but that you will get happy together too.

Lots of love and hugs will go a long way in helping children feel secure. Engage Gramma, Auntie, close friends to help with extra attention, and give children a break when you are able – a day at the beach, a weekend away, summer camp.

Anyone's Life Story – The Story of Kathleen



Putting Others Before Herself –

Kathleen Oikle was diagnosed with ALS in her mid 40's. After a few months of contemplating a move to a nursing home, Kathleen decided instead to use her life to raise awareness about ALS. Her family, friends, and community rallied around her, helping her build a float which she rode in the Apple Blossom, Halifax Natal Day, Gay Pride and many other community parades over the course of 3 summers. Kathleen is seen here hand painting the float with the assistance of a Hoyer Lift loaned to her by the ALS Society.

Your Healthcare Team and What They Do

Occupational Therapist - Occupational therapists help people who through disease or injury must adapt to how they perform everyday tasks – everything from mobility to personal care. O.T.'s will help you perform your daily functional tasks safely and efficiently. After conducting an assessment and talking to you, O.T.'s will be the members of your health care team that will most often recommend assistive devices and medical equipment.

Physical Therapist – A physical therapist (P.T.) has training in movement and function and can help you when you are experiencing difficulties with things like balance, walking, sitting up and standing up. P.T.'s also prescribe equipment and assistive devices. They may also teach you exercises for things like stretching and strategies for energy conservation.

Physiatrist – A physiatrist is a medical doctor who treats patients with temporary or permanent impairments due to injury or conditions such as ALS. Their training focuses on the nerves, muscles, and bones – parts of the anatomy which affect mobility and physical function.

Dietician – A dietician is an important member of your health care team, helping you with your nutrition needs, advice on food preparation, and food swallowing safety.

Speech Language Pathologist – An SLP will help you with strategies and recommend assistive devices to cope with speaking.

Respirologist – A doctor who will take care of your respiratory system (breathing).

Your ALS Clinic – Regular attendance at your ALS Clinic is invaluable. Your first few visits may seem overwhelming as you will see many different professionals from an occupational therapist to a dietician and more. The value comes from a multi-disciplinary team of specialists that are experienced in working with people with ALS. They can also confer with one another on the day you attend the clinic to adjust your care plan. Staff from ALS NB & NS are usually on site on clinic day as well to facilitate equipment loan requests and to be an extra shoulder to lean on. The team at the clinic can also monitor your disease progression which is also helpful in planning your care.

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Palliative Care

Words are so powerful. Often, our PALS (people living with ALS) and their families do not wish to access the services of Palliative Care because of the connection of the word with imminent end of life. Please know that this is not always the case. Palliative care services are broad in scope and will support your family in the goal of helping you live your best life as long as you can.

Palliative care is an approach to care for people who are living with a life-threatening illness, no matter how old they are. The focus of care is on achieving comfort and ensuring respect for the person with a terminal diagnosis and maximizing quality of life for the patient, family and loved ones.

Palliative care addresses different aspects of end-of-life care by:

- managing pain and other symptoms
- providing social, psychological, cultural, emotional, spiritual and practical support
- supporting caregivers
- providing support for bereavement

Palliative Care in Nova Scotia

The program is flexible, is administered by the Care Coordinator and is used in the last 6 months of a client's life. Due to the nature of the disease some clients with ALS are referred to the Palliative Care program even though they may not be in the last 6 months of their life. The person with ALS will be assessed for up to a maximum 12 hours per day of care at no cost. The clients spouse or care giver is given a budget of up to 40 hours a month respite care in addition to this for their personal use.

Medical Palliative Team – Medical Palliative Care is provided through Nova Scotia Cancer Care Center and is located in the Dixon Building. **The contact number is 473-6091.** The ALS Clinic staff will set up an appointment with this medical team when they feel it is the best time to open a file for your case. This team provides end of life medical palliative care and their goal is to provide medical assistance at the end of life. It is good to get this appointment completed early and then you will be in their client files and be able to access the services they offer. You will meet with a Doctor and Nurse and review where you currently are in the prognosis of your ALS.

The following are some of the items discussed during this meeting:

- Counseling is available for the client, spouse or couples
- A medical team will be provided to complement your existing care provided by Continuing Care.
- This team provides their services from your home or from the hospital.
- You have the opportunity to discuss your end of life concerns and establish what you would like to have happen.
- You are advised to write an advanced directive.
- You are given the opportunity to take home a DNR order so that those health professionals coming into your home know and can respect your wishes.

Palliative Care in New Brunswick

Palliative care in New Brunswick is arranged either privately, or through the provincial Extramural program, and is dependent on the region in which you live. Clients in New Brunswick who receive a diagnosis of ALS are usually automatically referred to the Extramural program for care. The Extramural program— also known as the “hospital without walls”— works to keep people in their homes as long as possible by providing professional in-home health services. Those services include registered nurses, licensed practice nurses, respiratory therapists, social workers, registered dietitians, occupational therapists, physiotherapists and speech-language pathologists. The Extramural program runs under Vitalite and Horizon Health networks.

If care needs should happen to increase to the point beyond where the caregiver and the Extramural program can keep the client at home comfortably and safely, then that is the point where a choice is made to arrange private care through a hospice, or transfer to the local hospital for palliative care. Please refer to links at the end of this document.

As part of Horizon health Network’s strategic plan for 2015-20, they have made a commitment to enhance primary palliative care teams and to create specialized palliative care teams. Vitalité Health Network’s 2017-2020 Strategic Plan includes a commitment to optimize services.

Medical Management of ALS

To date, there is no cure for ALS or treatments/drugs that slow progression more than three months. The influx of research funding due to the 2014 Ice Bucket Challenge have accelerated research greatly however , and it is anticipated that ALS will become a treatable, not fatal disease in the not-too-distant future.

There are a number of treatment strategies and equipment that will help you conserve energy and live a better quality of life for a longer period of time.

Early adaptation and adoption of intervention and treatment is helpful in the medical management of ALS and will make your days and your families' days a little easier.

The following is only a very brief introduction to the medical management of ALS and is designed to let you know what kind of help is available and to point you in the right direction to obtain more information.

Medication - The drug riluzole (Rilutek) is the only medication approved that in some people may slow the disease progression, perhaps by reducing levels of a chemical messenger in the brain (glutamate) that's often present in higher levels in people with ALS.

Riluzole may cause side effects such as dizziness, gastrointestinal conditions and liver function changes.

Your doctor may also prescribe medications to provide relief from other symptoms, including: muscle cramps and spasms, spasticity, constipation, fatigue, excessive salivation ,excessive phlegm ,pain, depression, sleep problems, uncontrolled outbursts of laughing or crying.

Source:

<http://www.mayoclinic.org/diseases-conditions/amyotrophic-lateral-sclerosis/diagnosis-treatment/treatment/txc-20247219>

Breathing – For most people breathing is an automatic function of the body. In ALS your breathing muscles and diaphragm weaken and breathing becomes difficult. At some point breathing difficulty will drain your energy that you want to preserve for other things. When this happens, you can choose to introduce some preventative measures. You will experience symptoms such as the inability to cough, difficulty having enough breath to speak long sentences, daytime headache, and overall tiredness. It is time to consider what is known as non-invasive ventilation. Some testing is involved and a bi-pap machine may be recommended. A bi-pap is a portable machine (the size of a shoe box) and comes with a tube and a mask. They are available for loan with a prescription from ALS NB & NS.

Speaking and Swallowing (Choking) /Nutritional Support- Your speech language pathologist and dietician will help you with these problems, recommending therapies, food preparation, assistive communication devices (available for loan with a prescription from ALS NB & NS). At some point you may have to consider being fed through a feeding tube. Naturally, most people find this a difficult decision and believe it means that the end is near. At ALS NB & NS we have witnessed many people who chose this route in order to meet their goals – i.e. living longer to be with children and other family. You can still be completely mobile with a feeding tube; you can still eat favourite things if you choose occasionally and under advice from your medical team. The care is very manageable and not as unpleasant

as may be imagined. Maintaining your weight with ALS is very important to help increase length of life. As well you may opt to have the feeding tube surgery while you are still able to eat and before your breathing is compromised.

Choking – Choking is something that everyone with ALS worries about. Please worry no further. It is a myth that you will die by choking. Choking is a manageable symptom that your healthcare team will provide strategies for you to reduce the risk.

Saliva Build Up – When tongue and throat muscles weaken in ALS; you may have difficulty expelling excess saliva and phlegm. This is the time to see a physiotherapist or a respirologist who will help you with strategies for assistive equipment such as a suctioning or cough assist machine which can be borrowed from ALS NB & NS with a prescription.

Mobility – Everyday activities such as getting in and out of bed, or a favourite lounge chair, walking, and taking a shower may be difficult as ALS progresses. It can be difficult to have medical equipment such as a patient lift, hospital bed, assistive devices in the bathroom, and a wheelchair all of a sudden appear in your home. But . . . they are important for your comfort, the prevention of falls and injury and will help you live as independently as possible. The decision about when to obtain equipment (available on loan from ALS NB & NS with a prescription) is one that you should make with your family and occupational therapist. When making the decision to access equipment you may also wish to consider the physicality involved of your caregiver in lifting you, helping you move, etc.

End of Life – Physician Assisted Death – This is not an easy topic for sure, but one that needs to be discussed with professionals (legal, finance, health care team) and your loved ones to ensure that people understand your wishes and why you made the decisions that you did. It helps your family carry out your wishes even when they may be uncomfortable with them.

A good on-line resource can be found at <http://www.advancecareplanning.ca/home.aspx>

You can revisit your decisions a couple of times a year. You may as you progress with the disease change your mind about certain things – getting a feeding tube or ventilation assistance, etc.

Make sure that your loved ones know where you keep your advance care plan and provide your medical team with a copy.

Physician assisted death was legalized in Canada in June 2015.

ALS New Brunswick and Nova Scotia is the life affirming ALS Advocate, established to help people and their families living with ALS navigate through a confusing and difficult disease with dignity and purpose.

Our purpose is to help ALS patients and their families manage their health and live in joy despite an overwhelming and unpredictable terminal diagnosis.

Our promise – YOU ARE NOT ALONE.

ALS NB & NS believes that there is a life of quality to be had of varying degree for most people after an ALS diagnosis. Further, ALS NB & NS will do everything possible to help someone diagnosed with ALS and their family to achieve quality of life.

ALS NB & NS will continue to advocate for strong palliative and end of life care for people living with ALS.

ALS NB & NS recognizes that quality of life can only be determined by the person living with ALS. ALS NB & NS commits to supporting those choosing physician assisted death with information on the law, the process, and emotional support.

Anyone’s Life Story- The Story of Judy

And so I began living my new life. Looking back, there are three words that summarize my new journey. The first is ACCEPTANCE. I knew that how I handled this was important to pave the way for this new road ahead. I made up a motto for myself and shared it with others, what I have, what I am and what I want. “I have faith and hope, I am optimistic and I will find joy every day.” I had to repeat it to myself several times during each day until I began to believe it myself. I looked for joy- “unexpected happiness” and began to find it in the most unexpected places.



ALS Society of New Brunswick and Nova Scotia Equipment Loans Program

The ALS Society of NB & NS operates an Equipment Loan Program that is designed to help people cope with the daily challenges of decreasing mobility and independence and to help families cope with the financial challenges of ALS. The Society tries to provide equipment that is cost prohibitive for most families. Items \$500+. This includes mobility equipment, basic communication devices, respiratory equipment, bath assist equipment, as needed.

Our goal is to keep people living with ALS:

- Comfortable
- Safe
- Breathing
- Communicative

- Mobile

This is a recycled equipment loan program. That is, our equipment serves more than one person and is used several times. It is cleaned and sanitized between uses and maintained by professionals when required.

We obtain equipment by purchasing new pieces when funding allows, by assisting with co-payment of insurance deductibles, and in-kind donations.

Equipment will be recommended to you by your occupational or physical therapist. Prior to purchasing the equipment, please talk to your ALS Champion.

- Your ALS Champion will work closely with your health care team to provide various types of assistive and mobility equipment as they are required.
- There is no needs testing and there are no rental fees to access the equipment loan program.
- There may be some minor set up and fees to adjust the equipment to fit your personal needs.
- The equipment is delivered to your home free of charge.

You need to do two things to access this equipment:

- (1) Complete \ brief [enrolment form](#) and submit it to tcooper@alsnbns.ca. The enrolment form can be found on our website alsnbns.ca.
- (2) Have a member of your health care team fax or email a prescription for the piece of equipment you require. Visit our website to download the form. www.alsnbns.ca
- (3) To request a Bi-Pap, Cough assist or suction machine. Have a member of your health care team fax or email a prescription for the piece of equipment you require.

visit our website to download the form. www.alsnbns.ca

Please feel free to contact ALS Champion Terri Cooper tcooper@alsnbns She is waiting to help you with your equipment needs.

Self-Referrals – Nova Scotia

If you are in need of immediate assistance for any services, you can contact your family doctor for referral. You can also self- refer to certain services such as Nova Scotia Hearing and Speech, Physiotherapy, Occupational Therapy and local dieticians. Referrals are required for Respiriology testing and referral can be obtain through the family doctor

Other Resources for Equipment

Canadian Red Cross

For more than 50 years the Canadian Red Cross has been offering Health Equipment Loan Programs. The Nova Scotia Region of the Canadian Red Cross includes eight full-time Service Centres located in Amherst, Antigonish, Bridgewater, metro Halifax (Burnside), Kentville, Sydney, Truro and Yarmouth.

Through the [HELP program](#) the Red Cross provides more than 50,000 pieces of health equipment to Atlantic Canadians every year, ranging from crutches and canes to specialized equipment such as wheelchairs. In Nova Scotia, the Red Cross also provides hospital beds for recovery or palliative care at home for individuals determined to be eligible after an assessment by care coordinators with the provincial Department of Health.

Other programs under the Community Health umbrella continue to flourish. Home Support Services are provided to clients in Nova Scotia and New Brunswick.

For further information:

<http://www.redcross.ca/article.asp?id=4987&tid=078>

<http://www.redcross.ca/article.asp?id=23801&tid=078>

<http://www.redcross.ca/article.asp?id=4987&tid=078>

Easter Seals – Nova Scotia

Easter Seals Nova Scotia's programs and services are directed to real needs in our communities: to help children, teens, and adults with physical disabilities to become more active, build independence and confidence, and gain access to equipment and information.

Wheelchair Recycling Program

In partnership with the Nova Scotia Department of Community Services, uninsured Nova Scotians aged 64 years or younger who meet the program criteria may obtain a wheelchair based on a medical prescription from a health care professional.

Contact Tamara Purcell, Wheelchair Program Assistant at (902) 453-6000, ext. 229 /Toll free at 1-866-554-4527 or email: wheelchairs@easterseals.ns.ca or visit the website to download an application form at:

<http://www.easterseals.ns.ca/programs-and-services/assistive-devices/>

- **Veteran's Affairs Benefits**

Veterans living with ALS will now be able to obtain the help and support they need and deserve, faster than ever before. These veterans will now be able to receive disability benefits, treatments and home care support services which are greatly needed by veterans and their families affected by ALS. For example, they will now be eligible for adapted wheelchairs, medical resources, housekeeping services and more. Given the wide variety of benefits and services that may be available, you are encouraged to contact VAC, toll-free at 1-866-522-2122; visit one of the District Offices across the country; contact the Royal Canadian Legion (http://legion.ca/ServiceBureau/overview_e.cfm), or any other Veterans' organization for further information and assistance.

Do I qualify? <http://www.veterans.gc.ca/eng/services/health/treatment-benefits>

Veteran's Affairs Canada Contact info & forms <http://www.veterans.gc.ca/eng/contact>

Most of the time, ALS NB & NS will be able to assist you with the loan of equipment. Other agencies are listed here should there be a wait list or should there be pieces of equipment ALS NB & NS does not provide.

Living the Gift Psychology Support Program

The Living the Gift Psychology Support Program is named after the late Charles Bower who lived with ALS and wrote a blog called Living the Gift. Charlie embraced life as it came to him and believed that life was a gift no matter the challenge.

With the help of the Association of Psychologists in NS and the College of Psychologists in New Brunswick, ALS NB & NS is pleased to refer people and their families living with ALS to a psychologist for help with coping with a terminal disease and other related issues. The help may be for the person living with ALS, for children or other immediate family members.

Please [contact your ALS Champion](#) for further information.

Support Groups

- For you and your family members.
- Real people offering real connection and support.
- In person or by Skype.

Discovering you are not alone is the most common reason for participating in support groups. With ALS it can be difficult to look down the road and see what is ahead. But . . . it can also calm you to see how people have coped as the disease progresses and give you confidence that with careful planning and a positive outlook, you will be able to cope as well.

For more information [contact your ALS Champion](#).

Other Resources

Society of Deaf and Hard of Hearing – Nova Scotia

The Society for the Deaf and Hard of Hearing Society has in the past loaned TTY systems to PALS unable to use their voice and has indicated that they will continue to do so should their client's needs be met.

A TTY system allows the user to place a phone call and then communicate through written text, rather than spoken communication. Systems include a telephone handset that is attached to a keyboard; each key makes a specific tone that can be read by the handset. The handset communicates those tones to a receiver on the other end of the line, and the receiver interprets the tones and generates a line of text.

Obviously, when someone places a call with a TTY system, they need to be certain that the recipient also has one. If the recipient has no TTY receiver, he or she will pick up the phone and hear a series of tones. In a situation where someone with a system needs to call someone without one, or vice versa, a telephone relay service is used. The relay service can read typed messages to callers who can hear, and turn spoken messages into text for deaf and hard of hearing callers.

Society of Deaf and Hard of Hearing Nova Scotians - Two Locations

56 Nepean Street 117

Sydney, NS, B1P 6A8

(902)564-0003 (voice/video phone/fax)

cbdeaf@ns.sympatico.ca

Society of Hard of Hearing for Nova Scotians

1657 Barrington Street

Halifax, NS, B3J 2A1 (902) 422-7130 (voice/videophone/tty)

(902) 564-0486 (TTY) (902) 492-3864 (fax)

1-888-770-8555 (toll free) 1-800-516-5551 (toll free)

Website: www.sdhhs.org

Email: sdhhs@ns.sympatico.ca

**South-East Deaf and Hard of Hearing Services and the Saint John Deaf and Hard of Hearing Service –
New Brunswick**

South-East Deaf and Hard of Hearing Services, Moncton (506-859-6101), and the Saint John Deaf and Hard of Hearing Services (506-633-0599) service most of New Brunswick. They have TTY systems for PALS unable to use their voice.

A TTY system allows the user to place a phone call and then communicate through written text, rather than spoken communication. Systems include a telephone handset that is attached to a keyboard; each key makes a specific tone that can be read by the handset. The handset communicates those tones to a receiver on the other end of the line, and the receiver interprets the tones and generates a line of text.

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Short term loans are available while your purchase is on order. There are subsidies available for those who qualify. Please contact your social worker for guidance.

South-East Deaf and Hard of Hearing Services Inc.

1690 West Main Street

Moncton, NB E1E 1G9

seds@nb.aibn.com

(506) 859-6101

Saint John Deaf and Hard of Hearing Services

324 Duke Street West

Saint John, NB E2M 1V2

sjdhhs@nb.sympatico.ca

(506) 633-0599

Meals on Wheels – New Brunswick

Meals on Wheels of Fredericton is an independent, non-profit organization dedicated to providing nutritious meals and social support for members of our community who have difficulty preparing meals for themselves. (506) 458-9482

<http://www.frederictonmealsonwheels.ca> (Meals On Wheels, Fredericton)

<http://www.nbinfo.ca/bresults.asp?SubjID=1352> (Meals On Wheels, NB)

Ability NB

Our mission is to empower the independence and full community participation of persons who have a spinal cord injury or mobility disability by providing innovative services and developing progressive public policy. Fredericton (506) 462-9555 Moncton (506) 858-0311

<http://www.abilitynb.ca/wp/>

Canadian Pension Disability Plan – New Brunswick and Nova Scotia

The Canada Pension Plan (CPP) disability benefit is a monthly payment. It is available to people who contributed recently to the Canada Pension Plan while they worked, and then became unable to work at any job on a regular basis because of a disability. The primary purpose is to replace a portion of employment earnings for people who recently paid into the CPP. There are also benefits for children if at least one parent qualifies for the CPP disability benefit.

A CPP disability benefit is not approved on the basis of which disability or disease you have, but on how the medical condition and its treatment affect your ability to work at any job on a regular basis. Please visit the website for more information and forms. <http://www.servicecanada.gc.ca/eng/isp/cpp/applicant.shtml#c>

Caregiver Benefit Program – New Brunswick and Nova Scotia

The Caregiver Benefit Program, formerly known as the Caregiver Allowance, recognizes the important role of caregivers in their efforts to assist loved ones and friends.

The program is targeted at low income care recipients who have a high level of disability or impairment as determined by a home care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive the Caregiver Benefit of \$400 per month.

Please visit the link to review eligibility checklist:

<http://www.servicecanada.gc.ca/eng/lifeevents/caregiver.shtml>

Housing Assistance for Persons with Disabilities- New Brunswick

For homeowners in need of disabled accessible modifications assistance is in the form of a forgivable loan up to a maximum of \$10,000. Additional assistance may be available in the form of a repayable loan based on a household's ability to repay.

Landlords are eligible for a forgivable loan for disabled modifications to a maximum of \$10,000.

The maximum forgivable loan for the creation of a secondary/garden suite or an extension to an existing dwelling is \$24,000. The applicant is required to produce equity or provide proof of other sources of financing to cover the cost of creating a secondary/garden suite or an extension which exceed the maximum forgivable loan available. The housing response to an applicant's particular situation is based on the needs of the applicant(s) and the most cost effective solution to address his/her current housing situation.

For more info and New Brunswick regional contact numbers visit:

http://www2.gnb.ca/content/gnb/en/services/services_renderer.19576.html

Disabled Residential Rehabilitation Assistance Program for Homeowners – Nova Scotia

The Residential Rehabilitation Assistance Program (RRAP) for Persons with Disabilities offers financial assistance to homeowners to undertake accessibility work to modify dwellings occupied or intended for occupancy by persons with disabilities. Funding is provided jointly by the Government of Canada (75%) and the Province of Nova Scotia (25%).

Hyperalimentation Program – New Brunswick

This program assists clients of the Social Services department with coverage for feeding supplies and formulas which are not covered by NB Medicare or private health insurance plans. This program is available to:

- Clients of the department and their dependents
- Individuals who have special health needs and who qualify for assisted health care under Section 4.4 of the Family Income Security Act and Regulations

There is no cost to eligible clients for entitled hyperalimentation supplies. Eligible services are paid monthly but quantities and frequencies are monitored. Please contact your social worker for more details on this program.

http://www2.gnb.ca/content/gnb/en/services/services_renderer.8055.Health_Services_Hyperalimentation_Program_.html

Insurance Coverage – New Brunswick and Nova Scotia

For those who have been diagnosed with ALS and continue to work, one of the things to consider is when and what to tell your employer. This is a personal decision depending on you and your employment situation. In light of a diagnosis of ALS, you may wish to consider exploring any extended healthcare benefits you might be eligible for. It is important to consider your current needs in addition to what may be required in the future, as there may be limits to what is provided. Consultation with your healthcare team is recommended while investigating these resources. **This can be done before telling your employer you have ALS.**

Some questions, you should ask yourself before making the decision to leave work are:

- Do you have access to benefits? (short & long term disability, banked sick time, EI benefits and CPP disability benefits).
- Do you enjoy work and does this change your quality of life that would be missing if you were unable to work?
- Are you still able to carry out your work duties safely?
- Do you still have the energy to continue working?

It is recommended that you do not sign any termination papers without consulting Human Resources to see if you are eligible for a severance package.

Contact your insurance provider to see what coverage you have available. Be sure to have all of the specific information about your insurance plan in front of you while calling.

Here is a list of questions:

- Is there an annual deductible?
- Is there a cap on my medical coverage? If so, is it yearly or a maximum amount?
- Does my plan cover prescription drugs and if so are there any drugs that would not be covered? (example Riluzole).
- Does my insurance cover pre-existing conditions?

- Does my plan cover durable medical equipment? Ask specifically what the coverage is for wheelchairs.
- Is there pre-authorization or quotes required?
- Does my plan cover Home Health Coverage and if so how do I access this service?
- Is there a specific Home Health Supplier I must use and if so, can you provide me with a list of contacts?
- Is there a maximum amount that is covered yearly if so what is the limit?
- Does my medical plan cover the cost of feeding tube supplies and formula?

All questions would apply to Group Medical Coverage. However, you will want to contact your provider exact coverage, loss of wages and deductible

Car Insurance – New Brunswick and Nova Scotia

Because of the ALS diagnosis you may want to speak to your physician and insurance provider to make sure that you still have good hand and foot control to operate a motor vehicle safely.

Parking Permits – New Brunswick

The Province of New Brunswick issues parking placards and permits for persons with disabilities to promote designated parking spaces for persons with disabilities.

The intent of this program is to limit eligibility for the parking permit and placard for person(s) having a disability to those situations where the person has a significant degree of mobility impairment or other health problems such that the person would have difficulty walking unassisted more than 50 metres in outdoor weather conditions. The placard and parking permit may be obtained upon application at Service New Brunswick Centres throughout the Province without charge. Applications must be signed by one of the following; a physician, occupational therapist, nurse practitioner or physiotherapist. Follow the link to download the application:

<http://app.infoaa.7700.gnb.ca/gnb/pub/EServices/ListServiceDetails.asp?ServiceID1=14197&ReportType1=All>

Taxes – New Brunswick and Nova Scotia

The disability tax credit is a non-refundable credit for eligible individuals. It reduces income tax payable on your income tax return. Eligibility is outlined on form TT2201 which is available on the Revenue Canada website. The application must be completed and signed by your doctor. It is advised that you send your application in prior to tax season to avoid delays. Visit the Revenue Canada website at:

<http://www.cra-arc.gc.ca/disability/>

New Brunswick Accessible Vehicle Tax Refund

Tangible Personal Property Tax and Provincial Vehicle Tax - the Minister may authorize a credit of tax paid on a specially equipped vehicle (either the 8% component of the Harmonized Sales Tax (HST) if the supply was made by a registrant, or the 13% Provincial Vehicle Tax (PVT) in the case of a private sale).

For more information you can call 1-800-669-7070

<http://www.gnb.ca/0048/pcsdp/directoriesforpersons/directoryofservices/Finance-e.asp>

The Community Volunteer Income Tax Program (CVITP) is a collaboration between community organizations and the Canada Revenue Agency. These organizations host free tax preparation clinics and arrange for volunteers to prepare income tax and benefit returns for eligible individuals for taxpayers with modest incomes. For more information you can call 1-800-959-8281, or visit,

<http://www.cra-arc.gc.ca/volunteer/>

- **The ALS Patient Registry - CNDR Registry / New Brunswick and Nova Scotia**

As of June 2011, a new national registry for patients with neuromuscular disease– the Canadian Neuromuscular Disease Registry (CNDR)– will help patients connect with researchers to participate in clinical research that will benefit patients by offering possible new therapies, treatments and understanding of their disease.

“This is a tremendous opportunity for patients, healthcare professionals, and researchers, to connect and improve research into neuromuscular diseases across Canada” says Dr. Lawrence Korngut the national principal investigator from the University of Calgary’s Faculty of Medicine, and a member of the Hotchkiss Brain Institute.

The CNDR is a Canada-wide database of patients who have been diagnosed with a neuromuscular disease. The term “neuromuscular disease” refers to a group of more than 40 diseases that affect how muscles and nerves work. ALS is the most prominent of these diseases in adults, and Duchenne muscular dystrophy (DMD) is the most common pediatric muscular dystrophy.

The Canadian Neuromuscular Disease Registry (CNDR) includes 17 clinics across Canada located in Vancouver, Calgary, Edmonton, Ottawa, Toronto, London, Kingston, Montreal and Halifax

Why participate?

The Registry is the only means by which valid national epidemiologic data about ALS can be obtained.

Patients with neuromuscular disease will benefit from this new national registry. Shelagh Mikulak has ALS and joined the registry because it gives her hope that “with the information available to researchers there will be a significant increase in the number of studies leading to discovering the cause, treatment and cure of ALS”.

Finding treatments for neuromuscular diseases has been challenging, as patients are scattered across the country. This registry will allow doctors and researchers to look at medical data from large groups of patients helping them to find better ways to manage each disease.

All patients, both adults and children, across Canada who have been diagnosed with a neuromuscular disease are able to join the registry. Patients living outside the cities with affiliated clinics, or those not currently seeing a neuromuscular specialist, can register by contacting the CNDR National Office at the University of Calgary at 1-877-401-4494.

The CNDR is supported by the ALS Society of Canada, Jesse's Journey and the Marigold Foundation. For more information about the registry please visit <http://www.cndr.org>

- **Self-Referrals**

If you are in need of immediate assistance for any services, you can contact your family doctor for referral. You can also self-refer to certain services such as Physiotherapy, Occupational Therapy and local dietitians. Referrals are required for Respiriology testing and, can be obtained through the family doctor.

- **Telehealth – New Brunswick**

The New Brunswick Telehealth Network (NBTHN) is a video conferencing communications network that connects healthcare focused facilities across New Brunswick. The NBTHN uses videoconferencing technologies to improve access to health services for patients, families and healthcare professionals.

Patients from across New Brunswick can meet face-to-face with health care professionals located anywhere on the network, without leaving their home communities. This saves patients the time, stress and expense associated with travel. Barriers to health care access including travel costs or inclement weather are removed.

Please check the link for a list, by region, of facilities and programs offering this service:

<http://en.horizonnb.ca/home/facilities-and-services/services/support-and-therapy/telehealth.aspx>

- **Tele-Health- Nova Scotia**

The Nova Scotia Tele-health Network (NSTHN) is a video conferencing communications network that connects healthcare focused facilities across Nova Scotia. The NSTHN uses videoconferencing technologies to improve access to health services for patients, families and healthcare professionals.

Patients from across Nova Scotia can meet face-to-face with health care professionals located anywhere on the network, without leaving their home communities. This saves patients the time, stress and expense associated with travel. Barriers to health care access including travel costs or inclement weather are removed.

The Tele-health is available to our ALS clients. If you would like to be seen via tele-health in your community, instead of travelling to Halifax, please contact Melanie Ellerker at the ALS Clinic 473-1245 to make arrangements.

- **Alternative Health**

Massage Therapy

ALS involves the degeneration of motor neurons but not sensory ones, and the client is fully aware of the changes occurring in his or her body. This combination of factors makes massage a great choice for many ALS clients because sensation is intact and the client can communicate about how the massage feels and what is needed. Gentle massage techniques are traditionally used on our ALS clients to help relieve stress, help with relaxation and comfort. This is a great therapy to help with joint stiffness and tightness in the muscles.

Remember to always use a licensed massage therapist for treatment and notify your therapist of any changes to your condition. You can contact the Association of New Brunswick Massage Therapists (ANBMT) for further information. Please call (506) 452-6972, or visit <http://www.anbmt.ca/anbmt/>

Remember, please consult your medical insurance provider for coverage information!

- **Acupuncture**

The medical definition of Acupuncture is one of the main forms of treatment in traditional Chinese medicine. It involves the use of sharp, thin needles that are inserted in the body at very specific points that are manipulated by the hands or by electrical stimulation. This process is believed to adjust and alter the body's energy flow into healthier patterns, and is used to treat a wide variety of illnesses and health conditions. When not delivered properly, acupuncture can cause serious adverse effects.

You will require a referral from a physician and it is always a good idea to check the credentials of your therapist. Please contact the Maritime Association of Registered Acupuncturists at <http://www.mar-atl.ca> for more information.

Be sure to communicate to your healthcare team about all alternative therapies you currently use.

Community Occupational Therapy & Physiotherapy Contacts – New Brunswick

CBI Health Centre (Moncton) 1 (506) 853-5144

pt Health Clinics: 1 (888) 998-4779

<http://www.pthealth.ca/new-brunswick-physiotherapy.php>

Rothesay, Moncton, Fredericton and Riverview

Hospital Listings – New Brunswick

New Brunswick's health services are delivered via two health authorities: Horizon Health Network and Réseau de santé Vitalité. These health authorities deliver health care services to residents and are responsible for all hospitals, community health services, mental health services and public health programs in their districts.

[Horizon Health Network 506-623-5500](http://www.horizonnb.ca)

[Fax: 506-623-5533](http://www.horizonnb.ca)

<http://en.horizonnb.ca/home.aspx>

Fredericton Area 506-452-5400

Miramichi Area 506-623-3000

Moncton Area 506-857-5111

Saint John Area 506-648-6000

Upper River Valley Area 506-375-5900

[Réseau de santé Vitalité 506-544-2133](http://www.vitalitenb.ca)

[Fax: 506-544-2145](http://www.vitalitenb.ca)

<http://www.vitalitenb.ca>

Chaleur Regional Hospital, Bathurst 506-544-3000

Campbellton Regional Hospital 506-789-5000

Charlotte County Hospital, St. Stephen 506-465-4444

Dr. Everett Chalmers Hospital, Fredericton 506-452-5400

Dr. Georges L. Dumont Hospital, Moncton 506-862-4000

Edmundston Regional Hospital 506-739-2200

Grand Falls General Hospital 506-473-7555

Grand Manan Hospital	506-662-4060
Hotel-Dieu St-Joseph, Saint Quentin	506-235-2300
Hotel-Dieu of Saint-Joseph, Perth-Andover	506-273-7100
L'Enfant-Jesus Hospital, Caraquet	506-726-2100
Miramichi Regional Hospital	506-623-3000
Moncton General Hospital	506-857-5111
Oromocto Public Hospital	506-357-4700
Restigouche Hospital, Campbellton	506-789-7000
Sackville Memorial Hosp.(secondary care)	506-364-4100
Saint John Regional Hospital	506-648-6000
St. Joseph's Hospital, Saint John	506-632-5595
Stella-Maris-de-Kent Hosp, Sainte-Anne-de-Kent	506-743-7800
Sussex Health Centre	506-432-3100
Tracadie-Sheila Hospital	506-394-3000
Upper River Valley Hospital, Waterville	506-375-5900

Community Occupational Therapy & Physiotherapy Contacts – Nova Scotia

South Shore Regional (Bridgewater)	527-2215
Queens General Hospital (Liverpool)	354-3575
Yarmouth Regional	742-3542 ext 137
Digby General	245-2502 ext 3257
Roseway Hospital (Shelburne)	875-4144 ext 204
Valley Regional (Kentville)	679-2770
Soldier's Memorial (Middleton)	825-3411 ext 358
Colchester Regional (Truro)	893-5520
Cumberland Regional Health Centre (Amherst)	667-5400 ext 6102 physio 667-5400 ext 6418 occupational
Pictou County Health Authority	755-7498
Antigonish Mall Business Centre	867-4745
Cape Breton Regional (Sydney)	567-7747 567-7748
Halifax (Joseph Howe Drive)	487-0622

You can self refer to access the services of an occupational or physiotherapist.

Hospital Listings – Nova Scotia

Nova Scotia's health services are delivered in nine district health authorities. These health authorities deliver health care services to residents and are responsible for all hospitals, community health services, mental health services and public health programs in their districts.

Annapolis Valley Health Authority - (902) 678-7381

Cape Breton Health Authority

- Buchannon Memorial Community Health Centre – 902-336-2200
- Cape Breton Regional Hospital – 902-567-8000
- Glace Bay Health Care Facility – 902-849-5511
- Harbourview Hospital - 902-736-2831
- Inverness Consolidated Memorial Hospital – 902-258-2100
- New Waterford Consolidated – 862-6411
- Northside General Hospital – 902-794-8521
- Sacred Heart Community Health – 902-224-1500
- Taigh Na Mara – 902-842-3900
- Victoria County Memorial Hospital – 902-295-2112

Capital Health District Hospitals

- Halifax Infirmary/Victoria General Sites (902) 473-2700
- Cobequid Community Health Centre - (902) 869-6100
- Dartmouth General Hospital - (902) 465-8300
- East Coast Forensic Hospital - (902) 460-7300
- Eastern Shore Memorial Hospital - (902) 885-2555
- Hants Community Hospital - (902) 792-2000
- Musquodoboit Valley Memorial Hospital - (902) 384-2220
- The Nova Scotia Hospital - (902) 464-3111
- Twin Oaks Memorial Hospital - (902) 889-2200

Colchester East Hants

- Colchester East Hants Health Authority – (902) 893-5554
- Lillian Fraser Memorial Hospital – (902) 657-2382

- Cumberland Health Authority – (902) 661-1090
- St. Martha's Regional Hospital - (902) 867-4500
- Pictou County Health Authority – (902) 752-7600

South Shore

- Fishermans Memorial (902) 634-8801
- Queens General (902) 354-3436
- Shore Regional (902) 543-4603

South West Regional

- Yarmouth Regional Hospital – (902) 742-3541
- RoseWay Hospital – (902) – 875-3011
- Digby General Hospital – (902) 245-2501

Point Pleasant Lodge – Nova Scotia

Point Pleasant Lodge is a privately owned and operated, not-for-profit specialty hotel, providing 100 guest rooms exclusively for people undertaking medical related travel in the Halifax area. This includes people who may be visiting patients in hospital or have appointments with doctors, dentists, ophthalmologists, etc.

We understand that medical related travel, which is often unplanned, introduces an additional financial burden. Our goal is to provide, clean, safe, and basic accommodations at reasonable rates. Please visit the website for further information: <https://pointpleasantlodge.com/>

Home Care & Living Independently

Extramural Program – New Brunswick

In-home care is offered in New Brunswick through the services of the New Brunswick Extra Mural program. Services are accessed through your OT. You can also contact your ALS Client Services manager Rachel MacNally @ 506-206-7727 for more information, or visit the link below.

Website: <http://en.horizonnb.ca/home/facilities-and-services/services.aspx?type=extra>

Private Home Care Agencies – New Brunswick

Kings County Home Care Services Ltd., Sussex (506) 433-5536 and Rothesay (506) 847-5295

We Care 1-866-729-3227

Integrity Home Health Services, Moncton (506) 383-1273, Fredericton (506) 454-1273, and Saint John (506) 657-1273

Bayshore Health Care 1-877-289-3997

The New Brunswick Home Support Association offers an agency search by your area:

<http://nbhsa.ca/english/home-care-agencies>

- **Helping Hand**

Helping Hand is based in the Saint John and Moncton areas, with service also available in Nova Scotia. They offer various services charged by an hourly rate. These services include light housekeeping, personal care, yard work and foot care, to name just a few. All staff are certified for their position, and there are RNs and LPNs on staff too. Please call 506-639-5879 for further information.

Victorian Order of Nurses

VON offers more than 75 different home care, personal support, and community services to enhance each client's quality of life by providing them with the personal assistance and the support needed to make them comfortable in their own home.

<http://www.von.ca/locations/Default.aspx?ProvId=4#List>

Nursing Homes – Nova Scotia

A variety of agencies and services are available in many communities. Some are privately owned and operated for profit (proprietary), others are affiliated with hospitals, and some are private non-profit agencies. Be sure to speak with your Continuing Care Coordinator regarding placements on waitlist. There is currently 8 months to a year wait list for placement.

Should a nursing home or some type of other assisted living facility become necessary please know that this is not the end of the road of you. Consider instead that it is a place to continue to live as long as you can as well as you can. Many of our PALS in nursing homes continue their outside social activities, use their computer to stay in touch with family and friends, and still stay in control of their medical decisions. Your ALS Champion from ALS NB & NS is happy to visit your chosen residence to help staff understand the special needs of someone living with ALS. Any equipment on loan from ALS NB & NS is available to you in a nursing home as well.

- **Lifeline**

Just over 30 years ago, Lifeline became the **first personal response and support service in Canada** dedicated to helping seniors, the physically challenged, and patients with medical conditions live confidently and safely at home. Lifeline Programs are based in hospitals, community agencies, and senior

living facilities. They are the backbone of our service network and ensure outstanding service delivery coast-to-coast. Please visit the website for further information:

http://www.lifeline.ca/content/english/medical_alert_service/how_lifeline_works/why_choose

- **MedicAlert Foundation Canada**

In a moment of crisis, paramedics, police and other emergency responders need to know your medical needs quickly. That information is critical when every second counts. “As a subscriber to one of our service plans, you’ll have the certainty of knowing that your MedicAlert ID will speak for you when you can’t speak for yourself.” <https://www.medicalert.ca/>

- **Hospice – New Brunswick**

The New Brunswick Hospice Palliative Care Association

<http://www.nbhpcasnb.ca/index.html>

Canadian Virtual Hospice

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/New+Brunswick/Local+palliative+care+programs_services.aspx

Contact and Program Information:

New Brunswick Extramural Program

Vitalite: <http://www.vitalitenb.ca/en/points-service/extra-mural-program>

Horizon: <http://en.horizonnb.ca/facilities-and-services/services.aspx?type=extra>

Residential hospices:

Bobby’s Hope House at Hospice Greater Saint John

Atlantic Canada’s first residential hospice is equipped with 10 private bedrooms, four family bedrooms, living rooms, kitchens, a dining room, playroom, onsite chapel, and garden. Pain and symptom management and 24 hour care is delivered by a team of doctors, nurses, staff and volunteers.

385 Dufferin Row, Saint John, NB, E2M 2J9

(506) 653-2995

info@hospicesj.ca

www.hospicesj.ca

Hospice Fredericton

Hospice Fredericton is a non-profit organization that has been actively providing volunteer based in-home support, grief support and respite care in the greater Fredericton and Oromocto area to those facing end-of life issues since 2009. Additionally, Hospice Fredericton now provides 24 hour care in a 10 bed residential hospice, for those patients that are at the end-of-life stage in a homelike, safe and supportive environment in which to spend their final days. Common spaces, chapel, rentable rooms for families are among some amenities available on site.

P.O Box 802, Fredericton, NB, E3B 5B4

506-472-8185

support@hospicefredericton.ca

<http://hospicefredericton.ca/>

Local Palliative Care Programs:**Hospice Fredericton**

Fredericton, NB

506-472-8185

support@hospicefredericton.ca

Hospice Greater Moncton

Moncton, NB

506-383-2404

info@hospicegm.ca

Hospice Greater Saint John, Inc.

Saint John, NB

506-632-5593

info@hospicesj.ca

Hospice of Charlotte

St. Stephen, NB

506-465-0800

director.hospice@nb.aibn.com

Hospice Sussex

Sussex, NB

506-432-5001

<http://hospicesussex.ca/>

Miramichi Regional Health Authority - Palliative Care

Miramichi, NB

506-623-3000
http://www.rha7.ca/mission_en.html#

The Moncton Hospital Palliative Care Program

Moncton, NB
506-857-5111
<http://en.horizonnb.ca/home/facilities-and-services/facilities/the-moncton-hospital.aspx>

Sackville Memorial Hospital Palliative Care Program

Sackville, NB
506-364-4154
educonsack@nb.aibn.com

South-East Hospice Sud-Est Inc.

Shediac, NB
506-533-9100
crcfb@nbnet.nb.ca

Tantramar Hospice Palliative Care Organization

Sackville, NB
506 364-8813
<http://www.thpco.ca>

Sources

http://www.alsclinic.pitt.edu/patients/pt_ot_therapy.php

<http://www.massgeneral.org/als/patienteducation/physicaltherapy.aspx>

<http://www.todaysdietitian.com/newarchives/tdoct2007pg84.shtml>

<https://www.aan.com/Guidelines/Home/GetGuidelineContent/373>

<http://alsn.mda.org/news/als-experts-keep-weight>

www.als.ca